

Cancer Patients' Informational Needs: Qualitative Content Analysis

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Abstract Understanding the informational needs of cancer patients is a requirement to plan any educative care program for them. The aim of this study was to identify Iranian cancer patients' perceptions of informational needs. The study took a qualitative approach. Semi-structured interviews were held with 25 cancer patients in two teaching hospitals in Iran. Transcripts of the interviews underwent conventional content analysis, and categories were extracted. The results came under two main categories: disease-related informational needs and information needs related to daily life. Disease-related informational needs had two subcategories: obtaining information about the nature of disease and obtaining information about disease prognosis. Information needs related to daily life also had two subcategories: obtaining information about healthy lifestyle and obtaining information about regular activities of daily life. The findings provide deep understanding of cancer patients' informational needs in Iran.

Keywords Cancer patients · Informational needs · Patients' perceptions · Content analysis

Introduction

Cancer is one of the main causes of death globally. It is an increasing problem in Middle Eastern countries. The Middle East includes a broad range of economically different countries, from industrial countries with high-rank cancer care to countries with little or no cancer cure capabilities. In the majority of countries of this region, cancer is usually diagnosed when it is at a highly developed stage [1]. In Iran, cancer is the third most common reason of death, after heart disease and road accidents. The incidence of cancer in Iran is anticipated to be around 48–112 and 51–144 cases per year per million people for women and men [2]. Iran is an ancient country placed in the Middle East with more than 5000 years of civilization and a population of about 70 million with a life expectancy of 71 years. Unhappily, the incorrect cultural ideas about cancer are still present among people demonstrating that the cancer taboo has not yet been broken and many Iranians consider cancer to be equivalent to death and end of life [3]. Therefore, it is important to explore patient's informational needs and stigmatizing beliefs about cancer so that targeted culturally relevant interventions can be developed to improve their wrong beliefs about cancer taboo.

Information regarding cancer diagnosis, treatment, and its probable effects can influence health consequences, decrease anxiety, and enhance feelings of control. As such, providing for patients' informational needs during their cancer journey is a significant element of their treatment [4]. Clear and sufficient information is vital for cancer patients in coping with the disease, accepting events through the line of cancer treatment and any outcomes, and participating in the decision-making process. The roles of information in cancer patients are recovering compliance, making rational expectations, increasing self-care and participation, and creating feelings of wellbeing and safety [5].

Many cancer patients perceive unmet informational needs about health promotion, and that perceived informational

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needs are associated to social, clinical, and behavioral factors [6]. In this regard, in spite of raising understanding of the value of patient information, cancer patients are still reporting several issues, including incomplete delivery of information in relation to timing and quality, incompatible or even opposing information, and a broad lack of information [5]. To meet cancer patients' informational needs, various support services are required. These services may take many forms, for instance, one-on-one counseling, educational programs, and information resource centers [6].

A variety of studies about cancer patients' informational needs has been documented in different countries. The findings of a qualitative study in the USA stated that patients tend to think of prognosis information as being only estimated limited survival and find the idea upsetting [7]. The results of a research in Canada explained that the informational needs of women with gynecologic cancers were grouped into six domains: medical, practical, physical, emotional, social, and spiritual [4]. Also, in a content analysis study, cancer information seeking preferences and experiences of older Chinese immigrant women to Canada were explored. Researchers found three main themes: sources of cancer information, barriers to cancer information seeking, and strategies used during information seeking [8]. In addition, the results of another study in Malaysia highlighted that the most important information required by breast cancer patients during the chemotherapy was followed by treatment, physical care, investigative tests, and psychosocial needs [9]. Another study indicated that 64.8 and 66.3 % of Korean cancer patients have unmet informational needs regarding healthy behaviors and nutrition [6].

Reviewing literature, we found that there are only a few qualitative studies on cancer patients' informational needs within the context of Iranian culture. Due to cultural differences, perceptions of affected Iranian cancer patients may be different from those of persons formerly studied. It is therefore appropriate to carry out a qualitative research in this area. The aim of this study was to identify the perceptions of Iranian cancer patients regarding their informational needs.

Methods

A qualitative research using conventional content analysis was conducted during 2014. Qualitative studies can prove helpful in explaining cancer patient's perspectives using their expressions about their informational needs in real and natural field. In other words, using qualitative approach in the present study can help the researcher enter into cancer patient's perceptual world and understand their perceptions about informational needs. We used the content analysis approach in this study. It is possibly the most common approach used in qualitative research. It is an organized coding and categorizing approach, which can be used to unobtrusively discover a large

amount of textual information. Through content analysis, it is probable to distill words into fewer content-related categories [10]. In present study, conventional content analysis was employed. It is usually used with a study design whose aim is to describe a phenomenon. It is generally appropriate when research evidence on a phenomenon is limited. Researchers immerse themselves in the data to allow novel insights to emerge, also described as inductive category development. In this approach, categories are obtained from data during data analysis. The benefit of the conventional content analysis is gaining direct data from study participants without imposing preconceived categories [10].

Participants

The research was carried out in the cancer wards of two teaching hospitals specializing in the treatment of cancer patients in Tehran, Iran. These wards have 15–32 beds. Participants were recruited from the cancer wards through purposeful maximum variation sampling. To ensure that all suitable patients were provided with a chance to participate, the wards were visited by the second author. The patients were notified that they had the right to withdraw from the study at any time. They were assured that their responses would remain confidential and that their identity would not be revealed in any phase of the study. Twenty-five patients took part: 14 females and 11 males. Their ages ranged from 32 to 51. Nineteen of the patients were married; the rest were single. The patients' level of study ranged from elementary school to bachelor's level, most of them (12 persons) had diploma. Regarding type of cancer, 9 persons had breast cancer, 7 persons colorectal cancer, 6 persons hematologic cancer, 2 persons gynecologic cancer, and 1 person lung cancer. The minimum time spent from diagnosis of disease was 2 months, and the maximum time was 4 years.

Data Collection

The ethics committee of Tehran University of Medical Sciences approved the study. The data collection was carried out after obtaining a signed informed consent form from the patients. Face-to-face, semi-structured individual interviews lasting around 40–55 min were held in convenient quiet locations on the cancer wards. Each participant was interviewed once. Therefore, 25 interviews were done. Over a period of 2 months, patients were interviewed by the second author at their centers of treatment. An interview guide was utilized, and the interviews were audio recorded. The interviews were performed in the Persian language by the second author. Those parts of the interviews that were relevant to this article were converted into English by an expert translator, and then, the English version was translated back into Persian for confirmation by the first author. The main question asked in the interviews was: "What is your perception of informational needs?" Probing questions

were also asked to follow the patients' ideas and make clear their responses during the interviews, such as: "Would you explain more about this?," "What is the meaning of that notion?," and "Could you please give me an example in order to help us correctly understand your point?"

The data collection and analysis proceeded concurrently. Once categories had been identified and data saturation reached, the interviews were terminated.

Data Analysis

Content analysis was used to categorize the interview data. The following steps were taken [10]:

- The interview transcripts were read several times in order to obtain a sense of the whole
- The text was separated into condensed meaning units
- The condensed meaning units were abstracted with codes
- The codes were arranged into subcategories and categories, based on assessments of their similarities and differences
- Categories were created as expressions of the hidden content of the text.

Trustworthiness was established [10]. Maximum variation sampling enhanced the confirmability and credibility of the data by ensuring its deepness and authenticity. The authors analyzed the results independently to recognize the initial codes and then compared their codes and categories. The credibility of the data was further established through member checking and peer checking. A brief of the interviews was returned to the patients, who verified that their perceptions were exactly represented. Peer checking was carried out by the authors and two doctoral nurses and resulted in similar findings.

Findings

The results came under two main categories: disease-related informational needs and information needs related to daily life. Disease-related informational needs had two subcategories: obtaining information about the nature of disease and obtaining information about disease prognosis. Information needs related to daily life also had two subcategories: obtaining information about healthy lifestyle and obtaining information about regular activities of daily life.

1. Disease-related informational needs

(a) Obtaining information about the nature of disease

The patients went through obtaining information about the nature, symptoms, and severity of diseases, when they were faced with clinical symptoms and at

primary stages of diagnosis. Some of them tried to acquire information about the nature and the reasons they have been afflicted with disease after they talked to their physician, because they did not know about the disease:

"The physician saw my tests and said you have a malignant tumor! I didn't know the meaning of this at all. They gave me some explanations, but I still didn't understand completely. I had too many questions. I wanted to know what it means. What kind of disease is it and how have I caught it?" (participant 5).

In order to obtain information, the patients referred to professional and non-professional sources, written materials, and Internet:

"I asked nurses. I got some journals to know more about this disease. I also used the internet" (P8).

Some patients stated that they were not aware of the symptoms and severity of disease before diagnosis.

"I was diagnosed with cancer and knew nothing about its symptoms nor about its severity" (P11).

(b) Obtaining information about disease prognosis

Most patients stated that they have ambiguities about the future of the disease:

"Will I have the energy I had before? Will I regain my efficiency? Will my condition improve or will it deteriorate?" (P2).

"I was just looking to know whether I will die or not? This is the question which patients with cancer at any age may ask" (P14).

"I asked if it were possible that my disease would recur. The physician said yes, it is possible" (P18).

The participant deemed it necessary to obtain information about the prognosis:

"If I know how far the disease has progressed, I will cooperate in its treatment and I will go under chemotherapy or radiotherapy regardless of the stage of disease. I can also make a good decision" (P13).

Most patients stated the case of hiding information about the negative diagnosis.

"The most important thing we need to know is how long will this disease affect our life? We have questions about our disease. We expect doctors and nurses to give us honest and direct information" (P15).

"...even if there is bad news, I am still eager to hear" (P22).

2. Information needs related to daily life

(a) Obtaining information about healthy lifestyle

The patients try to acquire information regarding type of nutrition, food limitation, exercise, and information to protect themselves.

“The food I should eat is important too. Cancer causes some food limitations for patient. It is important for me to know what foods I can eat and what I cannot. Food limitation is very hard” (P20).

“I cannot continue my life in the style I had before and eat whatever I like?” (P4).

“I asked: can I do heavy exercises? Can I go on walking as before? Doctors have told me you cannot do heavy exercises, they are dangerous for you, but you can go walking on flat levels like at the park” (P9).

(b) Obtaining information about regular activities of daily life

The patients were concerned about obtaining information regarding regular activities of daily life such as when to begin daily activities and when to start cooking, driving, and return to work and have sexual activities.

“I am eager to know when I can start my regular activities. When can I start cooking? When can I drive?” (P23).

Time of returning to work was vital especially for men because they are responsible for securing family economy and performing their social role:

“One of the men’s concerns is whether they will be able to return to work or not? The job is vital for them, and they are worried about how they can support their families without a job” (P12).

“Returning to work is a kind of social support for me. I think that a social assistant can help me and other patients in this case.” (P17).

The patients needed information about sexual matters too, but obtaining information in this regard was difficult for them:

“We need information about sexual matters but we have to ask furtively due to problems and cultural considerations” (P24).

“It is difficult to ask sexual questions, it is very hard, I am ashamed” (P3).

“I do apologize, the question I always wanted to ask but I never did was sexual disinclination. I could never ask about this” (P16).

Discussion

In the present study, information needs of patients with cancer included information needs related to disease and daily life. One of the classes of the research was the information needs related to disease which the patients understood by obtaining information about the nature of disease and the prognosis. In fact, when the patient is diagnosed with cancer, she/he requires so much information. Due to this fact, the participants tried to obtain information in order to recognize the nature of disease, its reason, and its influencing factors. The researchers in Canada and Malaysia stated that the major information needs of patients were regarding needs related to the nature of disease and its diagnosis [9, 11]. In China, the major information needs of patients were regarding nature of disease and its treatments [12]. In addition, since the participants were not aware of symptoms of disease and its severity, they felt that they need information in this regard. The result of one study revealed that level of awareness of Latino cancer patients concerning their disease was low, and these patients needed information about diagnosis of disease and its level of progress [13].

The participants said that they asked nurses and doctors in order to obtain information about the nature of disease. The result of a study in Canada revealed that the information needs of patients with cancer have been recognized by health care providers and they have responded [14]. The result of a study in the USA also revealed that the nurses and doctors provided patients with all the information they needed at all stages and types of cancer [7]. The researchers in Malaysia found out that, from the point of view of patients with cancer, the doctor can take measures to respond to the information needs of patients about the severity of disease, its treatment options, and news relevant to the disease [15]. Similarly, a study that was carried out with the participation of women with cancers who migrated from China to Canada revealed that these women obtained most of their information needs about their disease through their doctors [8]. Furthermore, the patients of the present study obtained some information through Internet. Patients with cancer in the USA and the Netherlands also used Internet for finding information [16, 17].

The participants wanted to know what will happen to them after infliction of sickness. Therefore, they tried to obtain information about the possibility to regain their previous power, improvement, progress of disease, and the possibility for living again. In this regard, the researchers in the USA stated that the information needs of patients with cancer were generally about staying healthy after treatment [16]. The patients said that obtaining information about their disease prognosis will make them more cooperative during treatment. The researchers in Canada stated that the major information need of patients with cancer was cooperation in treatment decision-making [11]. It seems that increasing information

of patients with cancer will affect their ability to cooperate in decision-making processes related to their treatment. While patients were trying to obtain information about the prognosis of disease, they expected nurses and doctors to treat them honestly; they hated not being told. The researches carried out in the USA and Iran revealed that nurses working in cancer wards were honest in treating patients and giving facts about the disease [18, 19]. The researcher relying on her clinical experiences thinks: Although telling the truth about cancer may result in unfavorable reactions, giving precise information to patients will help them better cope with their problems.

The participants believed that there was no correlation between the need to obtain information about disease prognosis and the patient's age. In this regard, the Italian researchers stated that the information needs of young and old patients with cancer were similar [20]. In addition, the participants said that obtaining information concerning the disease prognosis was not specific to a certain stage of disease. The researchers in the USA also stated: "there was no significant relation between information needs of patients with the stage of cancer" [21].

One of the other classes of our research was information needs related to daily life of patients with cancer. To this end, the patients emphasized on obtaining information about healthy lifestyle and regular activities of daily life. In this regard, the results of a study in Canada revealed that cancer has had many short-term and long-term effects on different dimensions of life of women afflicted with it [22]. Chinese researchers have also found that understanding different matters of patients with cancer with regard to all aspects of their lives will result in their improvement [23]. Hence, the importance of obtaining information about daily life of these patients is specified as a need.

For having a healthy life, the patients needed to obtain information about the amount of their activity, driving, walking, and doing exercises. They stated: "nutrition information was of significant importance for them concerning healthy lifestyle and they tried to obtain the most accurate information in this regard." One of the major information needs of Korean and Chinese patients was concerning nutrition information [12, 3]. The experience of researcher indicates that most patients face a shortage of nutrients during their disease, and those with better nutrition respond to treatment better. Therefore, it is very important to pay attention to information needs of patients in this field.

The patients believed that in case they wanted to return to their work and resume their regular activities, they needed social workers' services. The result of a study on women with cancer in Slovakia indicated that they also needed social workers' services [24]. The participant needed sexual information about regular activities of life, and this was accompanied by shame. The results of other studies carried out in the

USA and Iran revealed that patients with cancer needed information regarding their sexual needs [16, 25]. Obtaining sexual information is important for patients with cancer because it seems that if their needs in this regard are removed, their matrimonial relations will improve. But in Iran, it is culturally difficult for patients to talk about their sexual needs. Thus, these needs are probably neglected.

It seems obligatory to understand information needs of these patients while considering cultural grounds in order to respond to these needs and as a result to manage their lives efficiently. Dealing with this issue can be one of the substantial factors concerning improvement of educational services quality for these patients. Therefore, we can inform patients about the information needs through different educational methods such as holding group sessions and designing websites. Moreover, since the results of the study revealed that patients are faced with cultural obstacles with regard to their sexual needs, we can remove these obstacles by producing education programs on TV.

The results of this study have important clinical and research implications. These findings suggest that informational supportive services are needed for cancer patients in Iran. The development and implementation of educational programs tailored to the needs of cancer patients could potentially lead to comprehensive cancer care. Further qualitative research is obviously needed to more completely understand the informational needs of Iranian cancer patients. In fact, qualitative research that provides deep understanding of Iranian patients' informational needs, specifically related to problems associated with cultural stigma, such as sexual need, would provide significant insight.

Limitations

This research had some limitations as well. Choosing the patients was not based on a certain type or stage of cancer. The small sample size and the nature of the study limited the ability to generalize the findings. However, as with all qualitative studies, the results were not intended to be generalized. Nevertheless, the findings of this research add to the body of knowledge in this area.

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